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Examination of the Tripartite Model of Youth Caregiving in the Context of Parental Illness

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Examination of the Tripartite Model of Youth Caregiving in the Context of Parental Illness

Objective: This study refined the conceptualization of *youth caregiving* by testing the tripartite model of youth caregiving proposed by Pakenham and Cox (2015), comprising caregiving responsibilities, experiences, and tasks. We also investigated convergent validity of the model by examining the unique and joint contributions of the three youth caregiving components to youth adjustment outcomes. **Design:** A total of 681 Italian youth, 325 young carers and 356 non-carers, aged 11 to 24 years participated in a cross-sectional study. **Main outcome measures:** Participants completed a questionnaire assessing demographics, youth caregiving, and psychosocial adjustment. **Results:** Confirmatory factor analyses revealed that compared to a one-factor model, the three-factor youth caregiving model provided a better fit to the data in the young carer and non-carer subgroups. The three youth caregiving components predicted variations in youth adjustment. Caregiving experiences were the strongest predictor of poorer youth adjustment while caregiving tasks predicted improvement in two youth adjustment outcomes in diverse youth caregiving contexts. **Conclusions:** Findings support the validity of a three-factor model of youth caregiving, indicating that caregiving responsibilities, experiences, and tasks represent empirically distinct but related youth caregiving components. Interventions should mitigate the adverse and cultivate the positive effects of youth caregiving.

Keywords: young carers; caregiving responsibilities and experiences; caregiving tasks; parental illness or disability; youth adjustment

Introduction

Young people who assume responsibilities associated with caring for a parent with an illness or disability are referred to as young carers (Pakenham et al., 2006; Pakenham & Cox, 2014b). Estimates indicate that approximately 5% to 15% of children and adolescents (aged 4-18) live with a parent who is affected by a chronic illness (Worsham et al., 1997). However, these numbers are likely to be an underestimation because many young carers do not self-identify as carers (Aldridge & Becker, 1993). In addition, worldwide the prevalence of young carers is rising, not only because of the improved medical techniques that augment the life

expectancy of parents with chronic illness, but also because parents are conceiving children at an older age. In turn, older age is associated with an increased vulnerability to chronic illnesses and a greater likelihood that children will need to care for their aging parents (Morley et al., 2016; World Health Organization, 2020).

Most young carers care for a parent with illness or disability and are at elevated risk for mental, social, educational, and employment difficulties that persist well into adulthood (Chen & Panebianco, 2019; Chikhradze et al., 2017; Ireland & Pakenham, 2010b; Nagl-Cupal et al., 2014; Pakenham, 2009; Pakenham & Cox, 2012a, 2012b, 2014a, 2014b, 2015; Sieh et al., 2010). In fact, having a parent with a chronic illness is associated with significantly higher risk for internalizing problems (e.g., depressive, anxiety and somatic symptoms) and externalizing problems (e.g., aggressive and delinquent behaviors) (Chen & Panebianco, 2019; Chikhradze et al., 2017; Ireland & Pakenham, 2010b; Landi, Andreozzi, et al., 2020; Pakenham & Cox, 2012a, 2012b, 2014a, 2014b; Sieh et al., 2010). Young carers also report lower life satisfaction and poorer quality of life and often experience shame, guilt, and loneliness (Chikhradze et al., 2017; Pakenham et al., 2006; Pakenham & Bursnall, 2006; Pakenham & Cox, 2012a, 2012b, 2014a, 2014b). Compared to peers, youth of parents with a chronic illness are also at risk of affective dysregulation, stress-related somatic disorders, weakened immune responses, lower school performance, higher unemployment rates and fewer opportunities for personal pursuits (Armistead et al., 1995; Chikhradze et al., 2017; Morley et al., 2016; Rose & Coehn, 2010; Sieh et al., 2013). A recent study found that 10% of young carers reported intense sadness and frequently thought their life was not worth living (Kallander et al., 2018).

Previous research indicates that youth caregiving is a central construct in frameworks that account for how parental illness affects youth psychosocial outcomes (Chikhradze et al., 2017; Pakenham et al., 2006; Pakenham & Cox, 2012b, 2015). A major impediment to

research progress in this field is the lack of a clear conceptualization and operationalization of youth caregiving in the context of parental illness. In general, youth caregiving has emerged as a poorly formulated construct that has mostly been operationalized with respect to the behavioral component (i.e., involvement in specific caregiving activities), whereas the psychological components of caregiving have been neglected (Ireland & Pakenham, 2010a; Joseph et al., 2009; Kallander et al., 2018; Metzing et al., 2020; Nagl-Cupal et al., 2014; Pakenham et al., 2006). Hence, the main purpose of the present study is to further refine the conceptualization and measurement of this construct by testing a tripartite model of youth caregiving proposed by Pakenham and Cox (2015), which includes both behavioral and psychological components.

A tripartite model of youth caregiving

In the context of parental illness, families often meet illness demands by redistributing roles among family members, which often involves youth taking on more family caregiving activities (Pakenham et al., 2006). According to the Family Ecology Framework (Pedersen & Revenson, 2005), an important pathway that links parental illness to youth well-being is the redistribution of caregiving that occurs when a parent has a serious medical condition. Within this broader framework, Pakenham and Cox (2015) proposed a tripartite model of youth caregiving comprising: caregiving responsibilities, caregiving experiences, and caregiving tasks. This model is summarised in Table 1. Although Pakenham and Cox (2015) found empirical support for each of the three components, they did not test the full tripartite model of youth caregiving. Confirming the tripartite structure of youth caregiving will provide a clearer conceptualization of the construct, greater clarification of how best to measure it and delineation of those youth caregiving dimensions that should be targeted by services and interventions to reduce carer strain and associated mental health problems.

The first component of the tripartite model of youth caregiving is *caregiving responsibilities* which refers to the psychological sense of the duties or responsibilities related to caregiving activities that contribute to family functioning (Cox & Pakenham, 2014; Pakenham et al., 2006). In support of the role of this component, caregiving responsibilities have been shown to mediate the effects of parental illness on youth well-being such that higher parental illness severity is associated with an increase in caregiving responsibilities which, in turn adversely affects youth well-being (Pakenham & Cox, 2012b). A range of positive and negative psychosocial experiences are associated with youth caregiving responsibilities, which are collectively referred to as *caregiving experiences*, the second component of the tripartite model of youth caregiving. Caregiving responsibilities have been shown to predict increases in caregiving experiences (Pakenham & Cox, 2015). Qualitative (Bursnall & Pakenham, 2013) and quantitative (Cox & Pakenham, 2014; Pakenham et al., 2006) evidence suggests that there are five empirically distinguishable caregiving experiences that all youth potentially experience: perceived maturity, worry about parents, global activity restrictions, study/work activity restrictions, and isolation.

Finally, the third component of the tripartite model of youth caregiving is *caregiving tasks* which refer to specific caregiving activities that youth undertake, many of which are performed by youth who do not have parents with a chronic illness (e.g., shopping, cleaning) (Ireland & Pakenham, 2010a; Pakenham, & Cox, 2012a). Findings from factor analytic studies reveal four main dimensions to youth caregiving tasks: instrumental, personal-intimate, social-emotional, and domestic-household (Ireland & Pakenham, 2010b; Joseph et al., 2009).

To some extent most youth perform caregiving tasks and assume some responsibility for contributing to family functioning. Youth caregiving has been viewed as occurring on a continuum with basic household chores often undertaken by youth (e.g., cleaning) at the

lower end and at the higher end the assumption of caregiving responsibilities and activities at the expense of developmental needs (Becker, 2007; Hooper, 2007; Pakenham et al., 2006; Pakenham & Cox, 2015). Hence, all three model components of youth caregiving are applicable to diverse youth caregiving contexts, although they are likely to be intensified by illness in a family member, especially in parents (Cox & Pakenham, 2014; Pakenham et al., 2006; Pakenham & Cox, 2014b, 2015). Relative to caring for seriously ill non-parental family members, caring for an ill parent is associated with more intense youth caregiving responsibilities and experiences (Pakenham & Cox, 2015). Furthermore, studies show that compared to youth without a chronically ill parent, young people who have a parent with illness report higher levels of caregiving tasks (Chikhradze et al., 2017; Ireland & Pakenham, 2010a; Joseph et al., 2009; Kallander et al., 2018; Metzging et al., 2020; Nagl-Cupal et al., 2014; Pakenham et al., 2006) and caregiving responsibilities (Pakenham et al. 2006; Pakenham & Cox, 2012b, 2014a, 2015), and more intense caregiving experiences (Pakenham et al. 2006; Pakenham & Cox, 2012b, 2014a, 2015). In addition, at the global level higher youth caregiving responsibilities and care tasks, and more intense caregiving experiences are related to poorer mental health outcomes, including higher rates of psychological problems, poorer quality of life, more somatic complaints, isolation from peers (Bolas et al., 2007; Cassidy, 2013; Chikhradze et al., 2017; Kallander et al., 2018; Pakenham & Bursnall, 2006; Pakenham et al., 2007; Pakenham & Cox, 2012a, 2012b, 2015). However, some specific caregiving experiences (e.g., perceived maturity) and care tasks (e.g., social-emotional care) are associated with better youth adjustment outcomes, reflecting the potential costs and benefits derived from caregiving (Cox & Pakenham, 2014; Ireland & Pakenham, 2010a; Landi, Bocolini, et al., 2020; Pakenham et al. 2006).

The present study

While research findings provide support for the relevance of each model component to the overarching youth caregiving construct, no study has investigated the tripartite nature of youth caregiving in both young carers and non-carers. Hence, the first aim of the present study is to test the tripartite model of youth caregiving proposed by Pakenham and Cox (2015) in both young carers and non-carers. We predicted that the three-factor youth caregiving model is superior to a one-factor model in which all three components are grouped together. The second aim is to test the convergent validity of the model by examining relations between the three youth caregiving components and youth adjustment outcomes. We hypothesised that at the global level higher youth caregiving tasks and responsibilities and more intense caregiving experiences would be associated with poorer adjustment outcomes.

Method

Participants and recruitment procedure

A total of 681 Italian youth aged 11 to 24 years participated in the study between November 2018 and May 2019. Participants were recruited across Italy via brochures and posters in primary and secondary schools, universities, youth groups (e.g., library, music, and sports groups), illness-related local community organizations (e.g., cancer, epilepsy, and multiple sclerosis self-help and family support groups) and waiting rooms of health facilities (i.e., general practitioner, hospital and specialist clinics), as well as via posting on social networks. The study was advertised as “The Promotion of Mental Health and Well-being in Youth Project” and targeted youth living with or without an ill parent. Potential participants who showed interest in the study contacted the researchers. Eligibility criteria included living with or without a parent affected by a serious medical condition or disability and age 11 to 24 years. This age range was recently identified by a Lancet commission as a priority target for youth health and well-being research (Patton et al., 2016) and has been used in previous and ongoing youth caregiving studies (e.g., Chikhradze et al., 2017; Ireland & Pakenham, 2010a;

Pakenham et al., 2006, 2007; Metzging et al., 2020; Sieh et al., 2010). Exclusion criteria were insufficient command of Italian, cognitive impairments, and severe medical conditions in youth themselves, siblings or other family member apart from parents. The study was approved by the University of Bologna ethics committee. A researcher administered the hard copy questionnaire face-to-face, usually at the family home, after obtaining active informed consent from both parents if youth were underage or from youth themselves if they were ≥ 18 years. The variation in recruitment methods precluded the calculation of an overall response rate. Participants were considered ‘young carers’ if they reported having a parent with a serious medical condition and or disability, while ‘non-carers’ were those participants who did not have a parent with a serious medical condition or disability.

Measures

All participants completed a questionnaire consisting of the following questions and multi-item scales. For this study, we report on data from one section of the questionnaire completed by all participants. Consistent with previous research in this field, there was no requirement for self-identification of young carers (Gays, 2002; Pakenham et al., 2006). Participants were asked the following question: “Do you have a parent who has one of the following serious health conditions? – physical illness (e.g., cancer, diabetes, asthma), intellectual disability, physical disability (e.g., uses a wheel chair), alcohol/drug problem, mental illness (e.g., depression, anxiety, schizophrenia).” If they responded ‘yes’, they were considered young carers and completed additional questions about their parent’s illness described below. Cronbach’s alphas for all multi-item focal measures were $> .75$ for the total, and sub-group samples and are reported in Table 2.

Demographic and family structure variables

All participants provided information on their age (date of birth), gender, education, employment (“Do you have a paid part-time job”), ethnicity, dual or single-parent family, number of family members, and number, gender, and age of siblings.

Parental illness variables

Information on parental illness was obtained by questions and multi-item scales developed, validated and used in prior published youth caregiving research (e.g., Cox & Pakenham, 2014; Pakenham & Cox, 2012a, 2012b; 2014a, 2014b, 2015; Pakenham et al., 2006, 2007). Participants indicated whether any of their parents had a serious physical or mental health condition (‘yes/no’). If ‘yes’, they were asked to indicate which parent had a health condition (mother, father, both) and to name the health condition. Seriousness of illness: youth rated the seriousness of their parent’s health condition on a 5-point scale (1 *not at all serious* to 5 *very serious*). Parental functional difficulty: participants rated the extent to which their parent had difficulty performing daily activities as a result of their illness on a 5-point scale (1 *no difficulty* to 5 *extreme difficulty*). Illness unpredictability: youth rated on a 5-point scale (0 *strongly disagree* to 4 *strongly agree*) the extent to which they agreed with 5 items examining parental illness unpredictability (e.g., “My parent’s condition could change at any time with little warning”). Items scores were averaged with higher scores indicating higher illness unpredictability.

Caregiving experiences

Part A of the Italian version (Landi, Bocolini et al., 2020) of the Young Caregiver of Parents Inventory-Revised (YCOPI-R; Cox & Pakenham, 2014; Pakenham et al., 2006) was used to assess caregiving experiences. The YCOPI-R Part A measures generic youth caregiving experiences and therefore, can be completed by all youth irrespective of family caregiving demands (i.e., carers and non-carers). The Italian YCOPI-R Part A consists of a caregiving responsibilities subscale (described below) and five caregiving experience subscales:

perceived maturity (3 items; e.g. “I am more grown-up and mature than others my age”), worry about parents (3 items; e.g. “I always wonder if my parent (s) is/are safe”), activity restrictions global (3 items; e.g. “Helping my parent stops me from doing a lot of the things I want to do”), activity restrictions study/work (4 items; e.g. “I sometimes miss school/work because I have to help my parents”), and isolation (3 items; e.g. “Other people do not understand me and my situation”). All items are rated on a 5-point scale (0 *strongly disagree* to 4 *strongly agree*). Total or subscale caregiving experience scores are calculated by averaging items, with higher scores indicating more intense caregiving experiences. The internal reliabilities for the YCOPI-R Part A caregiving experience subscales in the derivation studies (range .78-.91; Cox & Pakenham, 2014; Pakenham et al., 2006) and in the Italian validation study (range .73-.84; Landi, Boccolini et al., 2020) were good. The YCOPI-R also demonstrated good content and predictive validity in the original and Italian validation studies (Cox & Pakenham, 2014; Landi, Boccolini et al., 2020; Pakenham et al. 2006). The original YCOPI-R Part A also exhibited partial measurement invariance across three groups of youth: youth with ‘healthy’ family members, youth of a parent with a significant medical condition, and youth of a parent with multiple sclerosis (Pakenham & Cox, 2014a).

Caregiving responsibilities

The Caregiving Responsibilities subscale of the Italian version (Landi, Boccolini et al., 2020) of the YCOPI-R (Cox & Pakenham, 2014; Pakenham et al., 2006) was used to assess caregiving responsibilities. It is composed of 7 items (e.g. “My parent(s) relies on me to help them with household chores”; “My parent(s) expect me to help care for them”) rated on a 5-point scale (0 *strongly disagree* to 4 *strongly agree*). Scores are averaged with higher scores indicating greater caregiving responsibilities. The subscale demonstrated good internal reliability in the derivation studies (Cronbach’s alpha of .84 and .85; Cox & Pakenham, 2014; Pakenham et al. 2006) and in the Italian validation study ($\alpha = .80$; Landi, Boccolini et al.,

2020). The caregiving responsibilities subscale has been used as an independent predictor in prior young carer research (Pakenham & Cox, 2012a, 2012b, 2014b, 2015, 2018).

Caregiving tasks

The 28-item Youth Activities of Caregiving Scale (YACS) (Ireland & Pakenham, 2010a) assesses the amount of help provided for specific caregiving tasks and it consists of four subscales: instrumental care (e.g., paying bills, and shopping), social-emotional care (e.g., providing emotional support and companionship), personal-intimate care (e.g., helping with dressing and toileting), and domestic-household care (i.e. helping with meal preparation and looking after siblings). Items are rated on a 5-point scale (0 *no help at all* to 4 *lots of help*).

Total or subscale scores are calculated by averaging items, with higher scores indicating a higher caregiving load. The YACS has good internal reliability (from .74 to .92) and both convergent and criterion validity (Ireland & Pakenham, 2010a; Pakenham, & Cox, 2012a).

The YACS development study was conducted with a sample of Australian young carers aged 10 to 25, with parents suffering from a range of chronic illnesses (Ireland & Pakenham, 2010a). In the only published Italian study using the YACS, the instrument demonstrated good internal reliabilities for the total scale and subscales in a sample of youth consisting of young carers and non-carers (.77 to .89), except for the domestic-household care subscale ($\alpha = .60$) (Landi, Boccolini et al., 2020).

Due to the poor internal reliability for the domestic-household care subscale, we ran a Confirmatory Factor Analysis (CFA) on the YACS using the total sample (Marsh et al., 2014). Fit indices of the CFA were inadequate for the original four-factor model: $\chi^2(343) = 1,828.36, p < .001$; CFI = .759; TLI = .735; RMSEA = .080; RMSEA CI = [.076, .083]; SRMR = .090. We then conducted an exploratory structural equation modeling (ESEM) analysis (Marsh et al., 2014) exploring the original four-factor solution which did not yield a satisfactory fit. Another ESEM was conducted exploring a three-factor solution, however 6

items did not meet the criteria set for allocating an item to a specific factor and were eliminated. A final ESEM was conducted on the remaining 22 items leading to a three-factor solution with satisfactory fit: $\chi^2(165) = 500.78, p < .001$; CFI = .928; TLI = .900; RMSEA = .055; RMSEA CI = [.049, .060]; SRMR = .033 (see table in the supplementary materials). The final Italian YACS had 3 factors: instrumental care, social-emotional care, and personal-intimate care. The domestic-household factor was not replicated in the Italian YACS.

Youth adjustment outcomes

Health-related quality of life (HRQoL). The Kidscreen-27 (Kidscreen Group Europe, 2006; Ravens-Sieberer et al., 2007) consists of 27 items measuring youth HRQoL across five dimensions: physical well-being, psychological well-being, autonomy and parent relations, peers and social support, and school/work environment ('work' was added to 'school' in items of this subscale, in order to make it more applicable to young adults). Items are rated on a 5-point Likert scale (0 *not at all* to 4 *extremely* or 0 *never* to 4 *always*). Raw scores were used in the analysis to allow for maximum variance (Kidscreen Group Europe, 2006). Total scores are calculated by summing all items, with higher scores indicating greater HRQoL. The Kidscreen-27 was validated in a large population-based sample of youth across various European countries, including Italy, and it exhibited good internal consistency, test-retest reliability and convergent and divergent validity (Ravens-Sieberer et al., 2007). It has been recently used with young people aged 16-35 years (Sepke et al., 2018) and it demonstrated metric age measurement invariance in the present study¹.

¹ Because the Kidscreen-27 (Kidscreen Group Europe, 2006) and the Youth Self-Report (YSR; Achenbach & Rescorla, 2001) in this study were applied to a wider age range than the validated age range, we examined measurement invariance across two age groups (youth aged 11-17 and those aged 18-24) by conducting multi-group CFAs. We examined both configural (the same number of factors and pattern of fixed and freely estimated parameters hold across groups) and metric invariance (equivalence of factor loadings). We considered the following changes in fit indices: $\Delta\text{CFI} \geq .010$ supplemented by $\Delta\text{RMSEA} \geq .015$ indicative of non-invariance (Chen, 2007, p. 501). Results indicated that metric invariance of both instruments was established (Kidscreen-27: $\Delta\text{CFI} = -.003$ and $\Delta\text{RMSEA} = 0.000$; YSR: $\Delta\text{CFI} = -.004$ and $\Delta\text{RMSEA} = .006$). This means that the Kidscreen-27 and the YSR factors have the same unit of measurement across the two age groups examined in this sample.

Internalizing and externalizing problems. The internalizing and externalizing problem scales of the Youth Self-Report (YSR) were used to assess emotional and behavioural functioning (Achenbach & Rescorla, 2001). The YSR internalizing scale reflects three dimensions: anxious/depressed, withdrawn/depressed, and somatic. The YSR externalizing scale has two dimensions: rule-breaking behaviours, and aggressive behaviours. Items are rated on a 3-point scale (0 *not true* to 2 *very true*). Scores are summed with higher scores indicating more problems. We used the validated Italian YSR (Frigerio et al., 2004). The original YSR has demonstrated sound psychometric proprieties including test-retest reliability (.79 to .88), internal consistency (.67 to .83) and content, criterion-related and construct validity (Achenbach & Rescorla, 2001). It has also been used with youth aged 10-25 years (Lum & Phares, 2005; Sieh et al., 2013) and evinced metric age measurement invariance in the present study¹.

Data analysis approach

Preliminary analyses (i.e., descriptive statistics, reliabilities, and correlations among study variables) were performed in IBM SPSS 24. Overall, the average percentage of missing data across all study items was 0.33%. Little's (1988) Missing Completely at Random test on the variables of interest yielded a normed χ^2 (χ^2/df) of 1.15. According to guidelines by Bollen (1989) this index, which can be used to correct for sensitivity of the χ^2 for large samples, is low and suggests that data are missing at random. Therefore, we used the Full Information Maximum Likelihood estimator in *Mplus* to address missing data. Second-order Confirmatory Factor Analyses (CFAs) used to test the tripartite model of youth caregiving were conducted in *Mplus* 8.4 with the robust maximum likelihood estimator (Muthén, & Muthén, 1998-2018). We tested the hypothesized model in which the three components of youth caregiving were considered as latent variables (three-factor model). Specifically, caregiving tasks constituted a second-order latent variable with instrumental, socio-emotional, and personal-intimate tasks

as first-order latent variables; caregiving responsibilities constituted a first-order variable; and caregiving experiences formed a second-order latent variable with perceived maturity, worry about parents, activity restrictions global, activity restrictions study/work, and isolation as first-order latent variables. Single items (when the latent variable was defined by less than five items) or parcels of items (when the latent variable was defined by five or more items²) constructed through the item-to-construct balance parceling method (e.g. Little et al., 2002) were used as observed indicators of the first-order latent variables. This hypothesized three-factor model was compared to a more parsimonious one-factor model, in which all first-order latent factors loaded on only one second-order latent variable. The one-factor and three-factor models were tested separately in the young carer and non-carer subgroups as well as in the total sample. The model fit was evaluated with the Comparative Fit Index (CFI), the Root Mean Square Error of Approximation (RMSEA) and its 90% Confidence Interval (CI), and the Standardized Root Mean Square Residual (SRMR). CFI values $> .90$, RMSEA values $\leq .08$, and SRMR values $\leq .09$ were considered indices of a good model fit (Marsh et al., 2005). Model comparisons were evaluated by changes in χ^2 and in model fit indices. To examine whether the one-factor or the three-factor model was the best fitting solution, we additionally compared the models using Akaike's Information Criterion (AIC) and Bayes Information Criterion (BIC) indices (i.e., the model with the smallest AIC and BIC values is the best fitting one). In order to examine convergent validity of the tripartite model of youth caregiving, we investigated the three components of youth caregiving as predictors of youth adjustment outcomes in a structural equation model in which caregiving responsibilities, experiences, and tasks were the exogenous variables and HRQoL, internalizing and

² In this condition, the parceling technique has several advantages, such as a more optimal sample size ratio indication (Bagozzi & Edwards, 1998) and a greater likelihood of achieving a good model solution (Marsh et al., 1998). For a further discussion of the advantages of parceling technique see Dimitrova et al. 2016 (for similar applications with other instruments used with youth see for instance, Crocetti et al., 2016; Morsünbül et al., 2014; Zimmermann et al., 2012).

externalizing problems were the endogenous variables. We controlled for demographics or family structure variables significantly correlated with youth adjustment outcomes. We conducted these analyses on the total sample and the young carer and non-carer subgroups. We also repeated the analyses with the various subscales of the tripartite structure of youth caregiving as exogenous variables. Multicollinearity was not a threat to the stability of the regression analyses as all tolerance values were low and in the acceptable range.

Results

Sample characteristics

A total of 681 Italian youth (60.4 % females) aged 11 to 24 years ($M = 17.80$, $SD = 4.01$) participated in this study. Of the total sample, 325 participants indicated they had a parent with an illness or disability, and they constituted the young carer subgroup, while 356 reported they had no parents with an illness or disability and they formed the non-carer subgroup. Regarding family structure variables, participants reported an average family size of 3.98 members ($SD = 0.98$). The mean number of older brothers and older sisters was 1.09 ($SD = 0.34$) and 1.06 ($SD = 0.24$), respectively. The mean number of younger brothers and younger sisters was 1.11 ($SD = 0.36$) and 1.08 ($SD = 0.27$), respectively. Most participants lived in a dual-parent family, with 6.8% living in a single-parent family. There were no significant differences between the young carer and the non-carer subgroups on demographic and family structure variables: age, $F(1,680) = 0.52$, $p = .47$; gender, $\chi^2 = 0.37$, $df = 1$, $p = .55$; currently studying, $\chi^2 = 0.03$, $df = 1$, $p = .96$; currently working, $\chi^2 = 1.39$, $df = 1$, $p = .24$; number of family members, $F(1,679) = 0.86$, $p = .36$; number of older brothers, $F(1,119) = 0.10$, $p = .75$; number of older sisters, $F(1,120) = 0.12$, $p = .91$; number of younger brothers, $F(1,121) = 0.70$, $p = .40$; number of younger sisters, $F(1,141) = 0.52$, $p = .47$; single-parent family, $\chi^2 = 0.10$, $df = 1$, $p = .75$.

Parent illnesses or disabilities were classified according to the International Classification of Diseases (11th ed.; ICD-11; World Health Organization, 2019) into: cancer (28.5%), type 1 and 2 diabetes (15.7%), neurological diseases (12.5%), substance use (12.5%), rheumatic diseases (7.1%), mental illnesses (6.7%), autoimmune diseases (2.6%), cardiovascular diseases (2.9%), gastrointestinal diseases (3.2%), respiratory diseases (2.2%), physical disabilities and musculoskeletal diseases (2.6%), infectious diseases (1.3%), diseases of liver, kidney and genitourinary system (1.6%), and others (0.6%). Among young carers, 60.6% reported having an ill mother, 32.6 % an ill father, and 6.8% both parents. The mean parental illness seriousness rating was 2.99 ($SD = 0.98$, range 1-5). The mean functional difficulty rating for parental illness was 2.05 ($SD = 1.12$, range 1-5) and the average parental illness unpredictability rating was 1.64 ($SD = 0.84$, range 0-4). Further descriptive data on the tripartite components of youth caregiving and youth adjustment outcomes in the young carer and non-carer subgroups, and total sample are presented in Table 2.

Compared to the non-carer subgroup, young carers reported significantly more intense caregiving on all three components of youth caregiving: caregiving responsibilities, $F(1,679) = 7.51, p < .01$; caregiving experiences, $F(1, 679) = 21.11, p < .001$; caregiving tasks, $F(1, 679) = 7.05, p < .01$.

Confirmatory factor analyses

The primary aim of the present study was to test the tripartite model of youth caregiving proposed by Pakenham and Cox (2015) in the total sample and in the young carer and non-carer subgroups. As predicted and displayed in Table 3, fit indices clearly indicated that the three-factor model provided the best fit to the data. In fact, compared to a one-factor model consisting of a single youth caregiving factor, the three-factor model resulted in substantial improvement in fit in the total sample ($\Delta\chi^2 = 227.496, \Delta df = 2, p < .001, \Delta CFI = .014, \Delta RMSEA = .004, \Delta SRMR = .005, \Delta AIC = 125.870, \Delta BIC = 116.481$), as well as in the

young carer ($\Delta\chi^2 = 45.485$, $\Delta df = 2$, $p < .001$, $\Delta CFI = -.010$, $\Delta RMSEA = .004$, $\Delta SRMR = .006$, $\Delta AIC = 48.569$, $\Delta BIC = 40.571$) and non-carer subgroups ($\Delta\chi^2 = 80.920$, $\Delta df = 2$, $p < .001$, $\Delta CFI = -.015$, $\Delta RMSEA = .005$, $\Delta SRMR = .000$, $\Delta AIC = 67.510$, $\Delta BIC = 59.502$). These results confirm the tripartite structure of youth caregiving comprised of three dimensions: caregiving responsibilities, caregiving experiences, and caregiving tasks. Standardized factor loadings for the three-factor model in the total sample are reported in Figure 1, which shows that caregiving responsibilities was positively related with both caregiving experiences and tasks (factor loadings .65 and .64, respectively in the total sample; .54 and .67 young carer subgroup, and .71 and .62 non-carer subgroup). In addition, caregiving experiences and caregiving tasks were positively related with each other (.46 in the total sample and the young carer subgroup and .43 in the non-carer subgroup).

Associations between the three components of youth caregiving and youth adjustment outcomes

The second aim of the present study was to examine the convergent validity of the tripartite model of youth caregiving by investigating the simultaneous relationships between each of the three youth caregiving components and youth adjustment outcomes. Of the demographic and family structure variables, only gender and age were significantly correlated with the youth adjustment outcomes. In particular, being younger and male was associated with better HRQoL (age, $r = -.20^{**}$, gender: $r = .18^{**}$, 1 = male), while being male was related to lower internalizing problems ($r = -.25^{**}$, 1 = male). For consistency, we controlled for both gender and age in all regression analyses. We first conducted multivariate regressions simultaneously entering caregiving responsibilities, experiences, and tasks as well as the confounders (i.e., gender and age) as predictors of HRQoL, internalizing and externalizing problems. We conducted these analyses on the total sample and the young carer and non-carer subgroups. Secondly, we repeated the analyses with the various subscales of the tripartite structure of

youth caregiving and the confounders as predictors. Correlations and standardized regression coefficients are displayed in Table 4.

Results of the two sets of analyses using the total scores of the three youth caregiving components and then their subscale scores, each explained significant amounts of variance in HRQoL (25% and 46% carer subgroup; 18% and 35% non-carer subgroup), internalizing problems (27% and 41% carer subgroup; 26% and 43% non-carer subgroup), and externalizing problems (8% and 17% carer subgroup; 7% and 14% non-carer subgroup).

The total caregiving experience score was the strongest predictor of poorer youth adjustment across all three outcomes in each of the three sample groupings. In particular, it predicted decreases in HRQoL (β s ranging from $-.36$ to $-.40$) and increases in both internalizing (β s ranging from $.44$ to $.48$) and externalizing problems (β s ranging from $.25$ to $.27$). Caregiving responsibilities did not predict any youth adjustment outcomes in the young carer and non-carer subgroups and total sample apart from the prediction of lower HRQoL in the young carer subgroup, which approached significance ($\beta = -.10, p = .055$). Finally, unexpectedly the total caregiving tasks score emerged as a predictor of improved youth adjustment across all three outcomes in both the young carer subgroup and total sample. Specifically, it was associated with increases in HRQoL (β s ranging from $.21$ to $.28$) and decreases in both internalizing (β s ranging from $-.11$ to $-.14$) and externalizing problems (β s ranging from $-.15$ to $-.18$). In the non-carer subgroup the total caregiving task score only predicted reductions in externalizing problems ($\beta = -.12$) and approached significance in predicting increases in HRQoL ($\beta = .12, p = .052$).

Regarding the second set of multivariate regression analyses using the subscales of the tripartite structure of youth caregiving, the caregiving experience subscale isolation was the strongest predictor of poorer youth adjustment across all three outcomes in each of the three sample groupings. In particular, it predicted decreases in HRQoL (β s ranging from $-.40$ to $-.40$)

.45) and increases in both internalizing (β s ranging from .54 to .57) and externalizing problems (β s ranging from .28 to .31). Of the other caregiving experience subscales, activity restrictions/global predicted decreases in HRQoL in each of the three sample groupings (β s ranging from -.15 to -.22) and perceived maturity predicted increases in HRQoL only in the young carer subgroup ($\beta = .12$). Of the caregiving task subscales, social-emotional care predicted increases in HRQoL (β s ranging from .16 to .19) and decreases in externalizing problems (β s ranging from -.12 to -.16) in each of the three sample groupings, while the instrumental care subscale predicted lower HRQoL only in the non-carer subgroup ($\beta = -.17$).

Discussion

The primary purpose of the present study was to refine the conceptualization and operationalization of youth caregiving by empirically validating the tripartite model of youth caregiving proposed by Pakenham and Cox (2015). As predicted, findings revealed that compared to a one-factor model, the three-factor model provided the best fit to the data, indicating that caregiving responsibilities, caregiving experiences, and caregiving tasks represent empirically distinct but related youth caregiving components (Pakenham & Cox, 2015; Pedersen & Revenson, 2005). Findings also suggest that the YCOPI-R and YACS are reliable measures of the psychological (caregiving responsibilities and experiences) and behavioural components, respectively, of youth caregiving in diverse contexts. Although youth caregiving is intensified by illness in a family member, especially in parents, results also demonstrated the utility of the tripartite model in both young carer and non-carer contexts. The empirical validation of the tripartite model of youth caregiving and the measurement of its components provides a theoretical framework to guide research into the mechanisms by which caregiving impacts youth mental health and the identification of those youth caregiving dimensions that should be targeted by preventive mental health services and interventions.

The second aim of this study was to test the convergent validity of the model by examining relations between the three youth caregiving components and youth adjustment outcomes. Consistent with prior research, at the bivariate level higher global scores for each of the three youth caregiving components were associated with poorer youth adjustment, although caregiving tasks was only weakly related to one outcome and this occurred in only the total sample analyses. However, when analyzing the joint and unique contributions of the three youth caregiving components in predicting youth adjustment outcomes, only caregiving experiences emerged as a significant predictor of poorer adjustment. Of the three caregiving components, the caregiving experiences variable was the strongest predictor of decreases in HRQoL, and increases in internalizing and externalizing problems. Consistent with prior research, the caregiving experience dimensions of isolation and activity restrictions imposed by the caregiving role emerged as predictors of poorer adjustment (Landi, Boccolini et al., 2020; Pakenham et al., 2006). Isolation, in particular, was the strongest predictor of decreases in HRQoL, and increases in internalizing and externalizing problems. Qualitative research on young carers highlights the propensity of young carers to feel isolated and different from their peers (Rose & Cohen, 2010). In fact, one of the most common themes reported by young carers is seeking ‘normalcy’ by concealing their caregiving role from others and thereby preventing stigma, especially if they care for a parent with mental illness or physical disability (Bolas et al., 2007; McDougall et al., 2018; Rose & Cohen, 2010). Young carer isolation has also been documented with respect to diminished opportunities for social interaction (e.g., not attending school or work, losing jobs and not fitting in with friends and peer groups) caused by caregiving restrictions on activities (Aldridge & Becker, 1993; McDougall et al., 2018).

In contrast, the caregiving experience dimension perceived maturity was associated with increases in HRQoL in young carers. One possible explanation for this finding is that greater self-perceived maturity indicates higher assumption of family caregiving roles and

responsibilities and greater family engagement, which in turn increases HRQoL. Pakenham et al. (2006) found that perceived maturity was associated with greater reliance on the acceptance and problem solving coping strategies which may also foster HRQoL. However, other authors argue that this perceived maturity might be a “false maturity” and that the reversal in parent-child role relations, which may occur in youth caregiving, adversely affects youth social-emotional development (Earley & Cushway, 2002).

Unexpectedly, the global caregiving tasks score emerged as a predictor of better HRQoL in the young carer subgroup, and less externalizing problems in both young carers and non-carers. Of the three global youth caregiving indicators, caregiving tasks was the only factor related to increases in youth adjustment. Consistent with this result, a prior study found the YACS total score was associated with greater prosocial behaviour (Ireland & Pakenham, 2010a), indicating participation in caregiving activities may promote prosocial behaviour. Alternatively, children who tend to engage in prosocial behaviour may become more involved in caregiving and hence, report better adjustment. In line with prior research findings, the social-emotional care dimension predicted improvements in adjustment (Cox & Pakenham, 2014; Ireland & Pakenham, 2010a; Pakenham et al. 2006). This finding suggests that participation in social and emotional care may play a key role in fostering youth adjustment. It is possible that engaging in such caregiving tasks facilitates closer connection between the young carer and the care-recipient and provides opportunities for deriving meaning from their caregiving (Chikhradze et al., 2007; Rose & Cohen, 2010).

The caregiving tasks subscale instrumental care was a significant predictor of decreases in HRQoL in the non-carer subgroup. One possible explanation is that, compared to young carers, non-carers resent the obligations of engaging in basic household chores which, in turn adversely affects HRQoL (Landi, Boccolini et al., 2020). It may also reflect the embedded cultural norm in Italy, whereby parents tend not to enforce their offspring to

actively participate in household chores, in part, to delay their domestic independence (Landi, Boccolini et al., 2020).

Overall, the aforementioned pattern of associations between the various caregiving dimensions and youth adjustment reflects the costs and benefits of youth caregiving that have been previously reported (Ireland & Pakenham, 2010a; Landi, Boccolini et al., 2020; Pakenham et al., 2006; Pakenham & Cox, 2014b, 2018). Results highlight the importance of considering not only the behavioral youth caregiving component, but also the psychological components of youth caregiving. Future research in this field should provide a clear conceptualization and operationalization of youth caregiving in view of the three caregiving components validated in the present study.

Regarding practice implications, mental health promotion interventions for young carers should target effective management of those caregiving dimensions associated with adverse adjustment outcomes. For example, isolation may be addressed by providing online forums where young carers can connect with other youth in similar circumstances. Interventions should also enhance the potential beneficial effects of youth caregiving dimensions associated with positive adjustment. For example, helping young carers to reflect on the meanings they derive from their caregiving activities. The benefits of youth caregiving also point to the need to support young carers in their role rather than replacing them. At a broader level, a whole family approach to supporting young carers is required given that caregiving is provided in the complex context of reciprocal intimate family relations (Aldridge & Becker, 2003).

This study also has several methodological limitations. First, the non-random sampling may increase volunteer response bias which limits the generalizability of results. However, participants were recruited from a wide range of facilities using diverse recruitment strategies, and young carers were not directly targeted. Second, because of the cross-sectional

design, it is not possible to make inferences about causal directionality among the three youth caregiving components, and youth adjustment outcomes. Longitudinal research is required to examine causal links among the three components of youth caregiving and youth adjustment outcomes over time. Third, the broad age range (11 – 24 years) of the sample encompasses numerous developmental phases. Nevertheless, a similar age range has been used in many prior young carer studies. In particular, the caregiving measures used in the present study were developed and validated using samples with a similar age range. In addition, we demonstrated age invariance of the instruments used to assess youth adjustment and we controlled for age in the predictive analyses. However, future research should explore potential interrelations among different developmental phases and the youth caregiving components. Fourth, participants were assigned to the younger carer group based on their having a parent with a serious health condition, but they were not asked whether they identified as a young carer. Hence, for youth who had a parent with an illness, it was not possible to determine whether identifying as a young carer impacted their caregiving and adjustment outcomes. Finally, Pakenham and Cox (2015) included in their proposed tripartite youth caregiving model an additional caregiving experience dimension specific to caring for an ill family member, which was not tested in the present study. This additional dimension is assessed by Part B of the YCOPI-R and was excluded from the present study because it requires further psychometric refinement.

In addition to addressing the abovementioned limitations, future research should examine the potential mediating and moderating roles of the three youth caregiving components in their relationships with youth adjustment. Future research should also investigate the differential links between the three caregiving components and a more diverse range of youth psychosocial outcomes, including benefit finding, which has been highlighted as a mental health protective factor for young carers (Pakenham & Cox, 2018).

Conclusion

Given the global rise in the number of youth caring for an ill or disabled family member and the association between youth caregiving and greater risks for mental and physical health problems, the negative consequences of youth caregiving are a significant public health issue. Findings from the present study provide empirical support for a tripartite model of youth caregiving which includes caregiving responsibilities, experiences, and tasks. This conceptual clarification of youth caregiving has the potential to advance our understanding and research into the links between parental illness and youth well-being. Importantly, the tripartite model is applicable to youth caregiving in the context of the presence or absence of parental illness. Results from this study suggest the YCOPI-R and the YACS are valid measures of the three youth caregiving components in both young carers and non-carers. These instruments may also help in identifying youth at risk for mental health problems and in evaluating young carer support services and preventive interventions. Results indicate that youth caregiving is a tripartite construct related to both positive and negative youth adjustment outcomes, suggesting support interventions should mitigate the adverse and cultivate the positive effects of youth caregiving.

Disclosure of interest

The authors report no conflict of interest.

Data availability statement

The dataset generated for this study is available on request to the corresponding author.

References

- Achenbach, T. M., & Rescorla, L. A. (2001). *Manual for ASEBA School-Age Forms & Profiles*. University of Vermont, Research Center for Children, Youth, & Families.
- Aldridge, J., & Becker, S. (1993). Punishing children for caring: The hidden cost of young carers. *Children & Society*, 7(4), 376–387. <https://doi.org/10.1111/j.1099-0860.1993.tb00293.x>
- Aldridge, J., & Becker, S. (2003). *Children caring for parents with mental illness: Perspectives of young carers, parents and professionals*. Policy Press.
- Armistead, L., Klein, K., & Forehand, R. (1995). Parental physical illness and child functioning. *Clinical Psychology Review*, 15(5), 409–422. [https://doi.org/10.1016/0272-7358\(95\)00023-I](https://doi.org/10.1016/0272-7358(95)00023-I)
- Bagozzi, R. P., & Heatherton, T. F. (1994). A general approach to representing multifaceted personality constructs: Application to state self-esteem. *Structural Equation Modeling: A Multidisciplinary Journal*, 1(1), 35–67. <https://doi.org/10.1080/10705519409539961>
- Becker, S. (2007). Global perspectives on children's unpaid caregiving in the family: Research and policy on 'Young Carers' in the UK, Australia, the USA, and Sub-Saharan Africa. *Global Social Policy*, 7(1), 23–50. <https://doi.org/10.1177/1468018107073892>
- Bolas, H., Wersch, A. V., & Flynn, D. (2007). The well-being of young people who care for a dependent relative: An interpretative phenomenological analysis. *Psychology & Health*, 22(7), 829–850. <https://doi.org/10.1080/14768320601020154>
- Bollen, K. A. (1989). *Structural equations with latent variables*. New York: Wiley.
- Burnsall, S., & Pakenham, K. I. (2013). Too Small for Your Boots! Understanding the experience of children when family members acquire a neurological condition. In H. Muenchberger, E. Kendall, & J. Wright (Eds.), *Health and healing after traumatic brain injury: Understanding the power of family, friends, community, and other support systems* (pp. 87–100). Praeger Publishers.
- Cassidy, T. (2013). Benefit finding through caring: The cancer caregiver experience. *Psychology & Health*, 28(3), 250–266. <https://doi.org/10.1080/08870446.2012.717623>
- Chen, F.F. (2007) Sensitivity of goodness of fit indexes to lack of measurement invariance. *Structural Equation Modeling*, 14 (3), 464–504. <https://doi.org/10.1080/10705510701301834>.
- Chen, C. Y. C., & Panebianco, A. (2019). Physical and psychological conditions of parental chronic illness, parentification and adolescent psychological adjustment. *Psychology & Health*. <https://doi.org/10.1080/08870446.2019.1699091>
- Chikhradze, N., Knecht, C., & Metzger, S. (2017). Young carers: Growing up with chronic illness in the family—A systematic review 2007-2017. *Journal of Compassionate Health Care*, 4(1), 12. <https://doi.org/10.1186/s40639-017-0041-3>
- Cox, S. D., & Pakenham, K. I. (2014). Confirmatory factor analysis and invariance testing of the Young Carer of Parents Inventory (YCOPI). *Rehabilitation Psychology*, 59(4), 439–452. <https://doi.org/10.1037/a0035860>
- Crocetti, E., Rubini, M., Branje, S., Koot, H. M., & Meeus, W. (2016). Self-concept clarity in adolescents and parents: A six-wave longitudinal and multi-informant study on

- development and intergenerational transmission. *Journal of Personality*, 84(5), 580–593. <https://doi.org/10.1111/jopy.12181>
- Dimitrova, R., Crocetti, E., Buzea, C., Jordanov, V., Kasic, M., Tair, E., Taušová, J., van Cittert, N., & Uka, F. (2016). The Utrecht-Management of Identity Commitments Scale (U-MICS): Measurement invariance and cross-national comparisons of youth from seven European countries. *European Journal of Psychological Assessment*, 32(2), 119–127. <https://doi.org/10.1027/1015-5759/a000241>
- Earley, L., & Cushway, D. (2002). The parentified child. *Clinical Child Psychology and Psychiatry*, 7(2), 163–178. <https://doi.org/10.1177/1359104502007002005>
- Frigerio, A., Cattaneo, C., Cataldo, M., Schiatti, A., Molteni, M., & Battaglia, M. (2004). Behavioral and emotional problems among Italian children and adolescents aged 4 to 18 years as reported by parents and teachers. *European Journal of Psychological Assessment*, 20(2), 124–133. <https://doi.org/10.1027/1015-5759.20.2.124>
- Gays, M. (2002). *Lifetime of caring: ACT schools-based young carers survey*. Marymead Child and Family Centre.
- Hooper, L. (2007). Expanding the discussion regarding parentification and its varied outcomes: Implications for mental health research and practice. *Journal of Mental Health Counseling*, 29(4), 322–337. <https://doi.org.ezproxy.unibo.it/10.17744/mehc.29.4.48511m0tk22054j5>
- Ireland, M. J., & Pakenham, K. I. (2010a). The nature of youth care tasks in families experiencing chronic illness/disability: Development of the Youth Activities of Caregiving Scale (YACS). *Psychology & Health*, 25(6), 713–731. <https://doi.org/10.1080/08870440902893724>
- Ireland, M. J., & Pakenham, K. I. (2010b). Youth adjustment to parental illness or disability: The role of illness characteristics, caregiving, and attachment. *Psychology, Health & Medicine*, 15(6), 632–645. <https://doi.org/10.1080/13548506.2010.498891>
- Joseph, S., Becker, S., Becker, F., & Regel, S. (2009). Assessment of caring and its effects in young people: Development of the Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) and the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) for young carers. *Child: Care, Health and Development*, 35(4), 510–520. <https://doi.org/10.1111/j.1365-2214.2009.00959.x>
- Kallander, E. K., Weimand, B., Ruud, T., Becker, S., Van Roy, B., & Hanssen-Bauer, K. (2018). Outcomes for children who care for a parent with a severe illness or substance abuse. *Child & Youth Services*, 39(4), 228–249. <https://doi.org/10.1080/0145935X.2018.1491302>
- Kidscreen Group Europe. (2006). *The KIDSCREEN Questionnaires: Quality of life questionnaires for children and adolescents*. Pabst Science Publishers.
- Landi, G., Andreozzi, M. S., Pakenham, K. I., Grandi, S., & Tossani, E. (2020). Psychosocial adjustment of young offspring in the context of parental type 1 and type 2 diabetes: A systematic review. *Diabetic Medicine*, 37(7), 1103–1113. <https://doi.org/10.1111/dme.14271>
- Landi, G., Boccolini, G., Giovagnoli, S., Pakenham, K. I., Grandi, S., & Tossani, E. (2020). Validation of the Italian Young Carer of Parents Inventory-Revised (YCOPI-R). *Disability and Rehabilitation*. <https://doi.org/10.1080/09638288.2020.1780478>

- Little, R. J. A. (1988). A test of missing completely at random for multivariate data with missing values. *Journal of the American Statistical Association*, 83, 1198–1202. <https://doi.org/10.1080/01621459.1988.10478722>.
- Little, T. D., Cunningham, W. A., Shahar, G., & Widaman, K. F. (2002). To parcel or not to parcel: Exploring the question, weighing the merits. *Structural Equation Modeling*, 9(2), 151–173. https://doi.org/10.1207/S15328007SEM0902_1
- Lum, J. J., & Phares, V. (2005). Assessing the emotional availability of parents. *Journal of Psychopathology and Behavioral Assessment*, 27(3), 211–226. <https://doi.org/10.1007/s10862-005-0637-3>
- Marsh, H. W., Hau, K. T., Balla, J. R., & Grayson, D. (1998). Is more ever too much? The number of indicators per factor in confirmatory factor analysis. *Multivariate Behavioral Research*, 33(2), 181–220. https://doi.org/10.1207/s15327906mbr3302_1
- Marsh, H. W., Hau, K.-T., & Grayson, D. (2005). Goodness of Fit in Structural Equation Models. In A. Maydeu-Olivares & J. J. McArdle (Eds.), *Contemporary psychometrics: A festschrift for Roderick P. McDonald* (pp. 275–340). Lawrence Erlbaum Associates Publishers.
- Marsh, H. W., Morin, A. J., Parker, P. D., & Kaur, G. (2014). Exploratory structural equation modeling: An integration of the best features of exploratory and confirmatory factor analysis. *Annual Review of Clinical Psychology*, 10, 85–110. <https://doi.org/10.1146/annurev-clinpsy-032813-153700>
- McDougall, E., O'Connor, M., & Howell, J. (2018). “Something that happens at home and stays at home”: An exploration of the lived experience of young carers in Western Australia. *Health & Social Care in the Community*, 26(4), 572–580. <https://doi.org/10.1111/hsc.12547>
- Metzing, S., Ostermann, T., Robens, S., & Galatsch, M. (2020). The prevalence of young carers—a standardised survey amongst school students (KiFam-study). *Scandinavian Journal of Caring Sciences*, 34(2), 501–513. <https://doi.org/10.1111/scs.12754>
- Morley, D., Li, X., & Jenkinson, C. (Eds.). (2016). *Children and young people’s response to parental illness: A handbook of assessment and practice*. Boca Raton, London and New York: CRC Press.
- Morsünbül, Ü., Crocetti, E., Cok, F., & Meeus, W. (2014). Brief Report: The Utrecht-Management of Identity Commitments Scale (U-MICS): Gender and age measurement invariance and convergent validity of the Turkish version. *Journal of Adolescence*, 37(6), 799–805. <https://doi.org/10.1016/j.adolescence.2014.05.008>
- Muthén, L. K., & Muthén, B. O. (1998-2018). *Mplus user’s guide*. (7th ed.). Muthén & Muthén.
- Nagl-Cupal, M., Daniel, M., Koller, M. M., & Mayer, H. (2014). Prevalence and effects of caregiving on children. *Journal of Advanced Nursing*, 70(10), 2314–2325. <https://doi.org/10.1111/jan.12388>
- Pakenham K. I. (2009). Children Who Care for Their Parents: The impact of parental disability on young lives. In C. A. Marshall, & E. Kendall (Eds.), *Disabilities: Insights from across fields and around the world* (pp. 39–60). Praeger Publishers.
- Pakenham, K. I., & Bursnall, S. (2006). Relations between social support, appraisal and coping and both positive and negative outcomes for children of a parent with multiple

- sclerosis and comparisons with children of healthy parents. *Clinical Rehabilitation*, 20(8), 709–723. <https://doi.org/10.1191/0269215506cre976oa>
- Pakenham, K. I., Bursnall, S., Chiu, J., Cannon, T., & Okochi, M. (2006). The psychosocial impact of caregiving on young people who have a parent with an illness or disability: Comparisons between young caregivers and noncaregivers. *Rehabilitation Psychology*, 51(2), 113–126. <https://doi.org/10.1037/0090-5550.51.2.113>
- Pakenham, K. I., Chiu, J., Bursnall, S., & Cannon, T. (2007). Relations between social support, appraisal and coping and both positive and negative outcomes in young carers. *Journal of Health Psychology*, 12(1), 89–102. <https://doi.org/10.1177/1359105307071743>
- Pakenham, K. I., & Cox, S. (2012a). The nature of caregiving in children of a parent with multiple sclerosis from multiple sources and the associations between caregiving activities and youth adjustment overtime. *Psychology & Health*, 27(3), 324–346. <https://doi.org/10.1080/08870446.2011.563853>
- Pakenham, K. I., & Cox, S. (2012b). Test of a model of the effects of parental illness on youth and family functioning. *Health Psychology*, 31(5), 580–590. <https://doi.org/10.1037/a0026530>
- Pakenham, K. I., & Cox, S. (2014a). Comparisons between youth of a parent with MS and a control group on adjustment, caregiving, attachment and family functioning. *Psychology & Health*, 29(1), 1–15. <https://doi.org/10.1080/08870446.2013.813944>
- Pakenham, K. I., & Cox, S. (2014b). The effects of parental illness and other ill family members on the adjustment of children. *Annals of Behavioral Medicine*, 48(3), 424–437. <https://doi.org/10.1007/s12160-014-9622-y>
- Pakenham, K. I., & Cox, S. (2015). The effects of parental illness and other ill family members on youth caregiving experiences. *Psychology & Health*, 30(7), 857–878. <https://doi.org/10.1080/08870446.2014.1001390>
- Pakenham, K. I., & Cox, S. (2018). Effects of benefit finding, social support and caregiving on youth adjustment in a parental illness context. *Journal of Child and Family Studies*, 27(8), 2491–2506. <https://doi.org/10.1007/s10826-018-1088-2>
- Patton, G. C., Sawyer, S. M., Santelli, J. S., Ross, D. A., Afifi, R., Allen, N. B., ... & Kakuma, R. (2016). Our future: a Lancet commission on adolescent health and wellbeing. *The Lancet*, 387(10036), 2423–2478. [https://doi.org/10.1016/S0140-6736\(16\)00579-1](https://doi.org/10.1016/S0140-6736(16)00579-1)
- Pedersen, S., & Revenson, T. A. (2005). Parental illness, family functioning, and adolescent well-being: A family ecology framework to guide research. *Journal of Family Psychology*, 19(3), 404–419. <https://doi.org/10.1037/0893-3200.19.3.404>
- Ravens-Sieberer, U., Auquier, P., Erhart, M., Gosch, A., Rajmil, L., Bruil, J., Power, M., Duer, W., Cloetta, B., Czemy, L., Mazur, J., Czimbalmo, A., Tountas, Y., Hagquist, C., Kilroe, J., & The European KIDSCREEN Group (2007). The KIDSCREEN-27 quality of life measure for children and adolescents: Psychometric results from a cross-cultural survey in 13 European countries. *Quality of Life Research*, 16(8), 1347–1356. <https://doi.org/10.1007/s11136-007-9240-2>
- Rose, H. D., & Cohen, K. (2010). The experiences of young carers: A meta-synthesis of qualitative findings. *Journal of Youth Studies*, 13(4), 473–487.

- <https://doi.org/10.1080/13676261003801739>
- Sepke, M., Ferentzi, H., Disselhoff, V. S. U., & Albert, W. (2018). Exploring the developmental tasks of emerging adults after paediatric heart transplantation: a cross-sectional case control study. *BMJ Open*, 8(11), e022461. <https://doi.org/10.1136/bmjopen-2018-022461>
- Sieh, D. S., Meijer, A. M., Oort, F. J., Visser-Meily, J. M. A., & Van der Leij, D. A. V. (2010). Problem behavior in children of chronically ill parents: A meta-analysis. *Clinical Child and Family Psychology Review*, 13(4), 384–397. <https://doi.org/10.1007/s10567-010-0074-z>
- Sieh, D. S., Visser-Meily, J. M. A., & Meijer, A. M. (2013). Differential outcomes of adolescents with chronically ill and healthy parents. *Journal of Child and Family Studies*, 22(2), 209–218. <https://doi.org/10.1007/s10826-012-9570-8>
- World Health Organization. (2019). *International statistical classification of diseases and related health problems* (11th ed.). <https://icd.who.int/>
- World Health Organization. (2020). *Noncommunicable diseases: Progress monitor 2020*. <https://www.who.int/publications-detail/ncd-progress-monitor-2020>.
- Worsham, N. L., Compas, B. E., & Ey, S. (1997). Children's coping with parental illness. In S. A., Wolchik, & I. N., Sandler (Eds.), *Handbook of children's coping* (pp. 195–213). Springer. https://doi.org/10.1007/978-1-4757-2677-0_7
- Zimmermann, G., Biermann, E., Mantzouranis, G., Genoud, P. A., & Crocetti, E. (2012). Brief Report: The Identity Style Inventory (ISI-3) and the Utrecht-Management of Identity Commitments Scale (U-MICS): Factor structure, reliability, and convergent validity in French-speaking college students. *Journal of Adolescence*, 35(2), 461–465. <https://doi.org/10.1016/j.adolescence.2010.11.013>

Table 1. Tripartite Model of Youth Caregiving.

Youth caregiving components	Description
1. Caregiving Responsibilities	Refers to the psychological sense of duty or responsibility related to roles involved in contributing to family functioning – assessed with the caregiving responsibilities subscale of the YCOPI-R Part A
2. Caregiving Experiences	<p>Refers to a range of psychosocial experiences emerging from taking on caregiving responsibilities. It is composed of a set of general caregiving experiences assessed with the YCOPI-R Part A as follows:</p> <ul style="list-style-type: none"> – <i>Perceived maturity</i>: Refers to the “adult child” theme and how taking on adult roles within the family can foster a sense of independence and personal growth – <i>Worry about parents</i>: Refers to worry and hypervigilance about the parent’s safety and health and monitoring of their parent for signs of health changes – <i>Activity restrictions global</i>: Refers to the interference of the caregiving role in many areas such as leisure time and socializing – <i>Activity restrictions study/work</i>: Refers to the interference of the caregiving role with school and/or work – <i>Isolation</i>: Refers to feelings of aloneness and difficulties in sharing caregiving experiences with others
3. Caregiving Tasks	<p>Refers to specific caregiving activities performed by young people assessed with the YACS</p> <p>It is composed by the following subscales:</p> <ul style="list-style-type: none"> – <i>Instrumental</i>: Refers to practical activities of daily living (e.g. transportation, managing finances and supervising medications) – <i>Social-Emotional</i>: Refers to providing emotional support and companionship (e.g., ensuring the ill parent is happy, gainfully occupied and safe) – <i>Personal-Intimate</i>: Refers to personal care tasks (e.g. toileting, changing dressings and assisting with mobility) – <i>Domestic-Household</i>: Refers to basic domestic duties (e.g. laundry, cooking, cleaning) and family care tasks

Notes. YCOPI-R = Young Carer of Parents Inventory-Revised (Cox & Pakenham, 2014); YACS = Youth Activities of Caregiving Scale (Ireland & Pakenham, 2010a). Adapted and modified from Cox & Pakenham, 2014, 2015; Ireland & Pakenham, 2010a.

Table 2. Descriptive data on demographics and family structure variables, parental illness variables, tripartite components of youth caregiving, and youth adjustment outcomes in the young carer and non-carer subgroups, and in the total sample.

Scale	Young carers (<i>n</i> = 325)				Non-carers (<i>n</i> = 356)				Total sample (<i>N</i> = 681)		
	%	<i>M</i> (<i>SD</i>)	Range	α	%	<i>M</i> (<i>SD</i>)	Range	α	%	<i>M</i> (<i>SD</i>)	α
<i>Demographics and family structure variables</i>											
Age years		17.92 (3.79)	11-24.92			17.70 (4.19)	11-24.99			17.80 (4.01)	
Gender: female	61.5				59.3				60.4		
Currently studying	82.2				82.3				82.2		
Currently working	30.8				26.7				28.6		
Family size		3.94 (1.09)	1-11			4.01 (0.86)	2-8			3.98 (0.98)	
Number of older brothers		1.10 (0.36)	1-3			1.08 (0.33)	1-3			1.09 (0.34)	
Number of older sisters		1.06 (0.24)	1-2			1.06 (0.23)	1-2			1.06 (0.24)	
Number of younger brothers		1.08 (0.27)	1-2			1.13 (0.42)	1-3			1.11 (0.36)	
Number of younger sisters		1.06 (0.24)	1-2			1.09 (0.29)	1-2			1.08 (0.27)	
Single parent family	7.1				6.5				6.8		
<i>Tripartite components of youth caregiving</i>											
1. Caregiving Responsibilities		1.53 (0.79)	0-3.9	.79		1.37 (0.77)	0-3.71	.79		1.45 (0.78)	.79
2. Caregiving Experiences		1.76 (0.58)	0.27-3.9	.83		1.56 (0.52)	0.07-3.25	.80		1.66 (0.55)	.82
Perceived Maturity		2.45 (0.94)	0-4	.82		2.07 (0.98)	0-4	.84		2.25 (0.98)	.84
Worry about Parents		2.91 (0.87)	0-4	.84		2.89 (0.85)	0-4	.84		2.90 (0.86)	.84
Activity Restrictions Global		1.09 (0.92)	0-4	.83		0.87 (0.74)	0-3.67	.70		0.97 (0.84)	.78
Activity Restrictions Study/Work		0.56 (0.75)	0-3.75	.87		0.38 (0.60)	0-3.25	.84		0.47 (0.68)	.86
Isolation		1.76 (1.10)	0-4	.76		1.61 (1.03)	0-4	.78		1.68 (1.07)	.77
3. Caregiving Tasks		1.19 (0.53)	0.05-3.05	.86		1.08 (0.54)	0-2.95	.88		1.13 (0.53)	.88
Instrumental Care		0.95 (0.79)	0-3.67	.78		0.85 (0.76)	0-4	.79		0.90 (0.78)	.78
Social-Emotional Care		2.13 (0.77)	0-4	.84		2.02 (0.83)	0-4	.87		2.07 (0.81)	.86
Personal-Intimate Care		0.42 (0.63)	0-3.63	.88		0.32 (0.55)	0-3.50	.88		0.37 (0.59)	.88
<i>Youth Adjustment Outcomes</i>											
Total HRQoL		94.80 (15.96)	39-126	.92		98.20 (12.80)	55-129	.88		96.57 (14.49)	.91
Internalizing Problems		16.04 (10.15)	0-42	.90		13.88 (8.87)	0-50	.89		14.91 (9.56)	.90
Externalizing Problems		10.23 (6.84)	0-41	.84		9.05 (6.06)	0-33	.82		9.85 (6.45)	.83

Table 3. Fit indices for the one-factor and three-factor models of youth caregiving in the young carer and non-carer subgroups, and in the total sample.

	Model fit indices						
	χ^2	<i>df</i>	CFI	RMSEA [90% CI]	SRMR	AIC	BIC
<i>One-factor youth caregiving model</i>							
Young carers (<i>n</i> = 325)	692.885	341	.918	.051 [.045, .056]	.090	24,748.746	25,120.647
Non-carers (<i>n</i> = 356)	699.505	341	.913	.051 [.046, .056]	.080	24,341.615	24,713.977
Total sample (<i>N</i> = 681)	985.023	341	.922	.048 [.045, .052]	.080	49,168.660	49,605.254
<i>Three-factor youth caregiving model</i>							
Young carers (<i>n</i> = 325)	644.805	339	.928	.047 [.042, .053]	.084	24,700.177	25,080.076
Non-carers (<i>n</i> = 356)	634.923	339	.928	.046 [.041, .052]	.080	24,274.105	24,654.475
Total sample (<i>N</i> = 681)	867.594	339	.936	.044 [.040, .048]	.075	49,042.790	49,488.773

Note. χ^2 = Chi-square; *df* = degrees of freedom; CFI = Comparative Fit Index; RMSEA = Root Mean Square Error of Approximation; CI = confidence interval; SRMR = Standardized Root Mean Square Residual; AIC = Akaike's information criterion; BIC = Bayes Information Criterion.

Bold indicates the best fitting factor solution for each group.

Table 4. Associations of the three components of youth caregiving and youth adjustment outcomes, in the young carer ($n = 325$), and non-carer subgroups ($n = 356$), and in the total sample ($N = 681$).

Variable	Health-related Quality of Life			Internalizing Problems			Externalizing Problems		
	YCs β (r)	NCs β (r)	TS β (r)	YCs β (r)	NCs β (r)	TS β (r)	YCs β (r)	NCs β (r)	TS β (r)
1. Caregiving Responsibilities	-.10 [†] (-.22***)	.00 (-.09)	-.07 (-.17***)	.09 (.28***)	-.04 (.12*)	.03 (.21***)	.07 (.14*)	.02 (.07)	.05 (.11**)
2. Caregiving Experiences	-.40*** (-.40***)	-.36*** (-.35***)	-.40*** (-.39***)	.44*** (.48***)	.48*** (.46***)	.47*** (.48***)	.26*** (.22***)	.25*** (.20***)	.27*** (.22***)
Perceived Maturity	.12* (.07)	.04 (-.10)	.06 (-.11**)	-.05 (.16**)	-.07 (.12*)	-.05 (.16***)	.07 (.10)	-.03 (.03)	.02 (.08)
Worry about Parents	.08 (.11)	.07 (.06)	.07 (.08*)	.02 (.10)	.04 (.14**)	.01 (.12***)	-.10 (-.11*)	.06 (.03)	-.03 (-.04)
Activity Restrictions Global	-.22*** (-.38***)	-.15* (-.30***)	-.18*** (-.36***)	.08 (.31***)	.09 (.28***)	.09 (.31***)	.04 (.20***)	-.03 (.12*)	.02 (.17***)
Activity Restrictions Study/Work	-.01 (-.27***)	-.05 (-.18***)	-.03 (-.25***)	.03 (.24***)	.01 (.15**)	.02 (.22***)	.00 (.13*)	.02 (.09)	.01 (.12***)
Isolation	-.45*** (-.55***)	-.40*** (-.49***)	-.42*** (-.53***)	.54*** (.60***)	.57*** (.62***)	.56*** (.61***)	.28*** (.33***)	.31*** (.30***)	.30*** (.32***)
3. Caregiving Tasks	.28*** (.08)	.12 [†] (-.03)	.21*** (.02)	-.14* (.09)	-.08 (.10)	-.11** (.10**)	-.18** (-.07)	-.12* (-.04)	-.15*** (-.05)
Instrumental Care	-.01 (-.05)	-.17** (-.21***)	-.06 (-.13***)	-.07 (.06)	.04 (.14**)	-.06 (.11**)	-.04 (-.03)	.06 (.06)	.03 (.02)
Social-Emotional Care	.19*** (.24***)	.16* (.09)	.17*** (.16***)	.04 (.04)	.07 (.09)	.06 (.07)	-.16* (-.18***)	-.12* (-.06)	-.14** (-.11**)
Personal-Intimate Care	.00 (-.06)	.04 (.01)	.01 (-.04)	.00 (.10)	-.03 (-.02)	-.01 (.06)	-.09 (.09)	-.05 (-.08)	.00 (.02)
R ² total scores/ with subscales	.25*** /.46***	.18*** /.35***	.22*** .40***	.27*** /.41***	.26*** /.43***	.27*** /.42***	.08** /.17***	.07* /.14***	.08*** /.13***

Note. [†] $p < .10$, * $p < .05$, ** $p < .01$, *** $p < .001$. YCs = young carers, NCs = non-carers, TS = total sample, β = standardized beta coefficient, r = Pearson's correlation.

Figure 1. Standardized solution of the three-factor structure depicting the three components of young caregiving in the total sample as well as the young carer and the non-carer subgroups.

Notes. All factor loadings and correlations are significant at $p < .001$. In parenthesis are factor loadings for young carers and non-carers, respectively.